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15th February 2022

Deputy Bernard Durkan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: bernard.durkan@oireachtas.ie

Dear Deputy Durkan,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 5757/22

To ask the Minister for Health the degree to which services for persons with disabilities are in line with best international practice; and if he will make a statement on the matter

HSE Response

In Ireland, a wide range of disability services are provided to those with physical, sensory, intellectual disability and autism. Disability services focus on supporting and enabling people with disabilities to maximise their full potential, as independently as possible. Disability services strive to ensure the voices of service users and their families are heard, and are fully involved in planning and improving services to meet their needs. Current policies are based on the principles of person-centredness to ensure insofar as possible that the supports for a person are based on individual assessed need, will and preference and to support people to remain as close to home and connected to their community as possible.

In 2021, Disability Services has been allocated c. €2.2 billion to provide a range of services throughout the country and is spent in line with nationally agreed policy for disability services, whilst at the same time endeavouring to maximise value. Services include Residential and Respite Services, Day Services, PA and Home Support Services, and Therapeutic Supports.

The needs of people with a disability extend well beyond health service provision, and the health service participates fully with other Government departments and services in the development of cross-sectoral strategies to maximise access to services and supports for people with disabilities.

In this context, there is a collective effort being made nationally and regionally to fundamentally reform how we deliver services for people with a disability and our commitment to uphold the UN Convention on the Rights of People with a Disability. Under the Transforming Lives policy, this has been a driving force of strong collaborative efforts over many years and where real progress has and continues to be made.

The key focus of the Transforming Lives Programme is to support people with disabilities to 'live ordinary lives in ordinary places' and to reconfigure disability services and supports to achieve this critical aim. There are a number of HSE policies under the framework of *Transforming Lives* that guide HSE policy and plans and all of these are based on best international practice and up-to-date research on a range of international initiatives aimed at promoting and supporting models of community inclusion and person-centredness. These policies also align with the UN Convention on the Rights of People with Disabilities, and include *Time*



to *Move on from Congregated Settings; New Directions; and Progressing Disability Services for Children & Young People.*

A Time to Move on from Congregated Settings

In June 2011 the Report “Time to Move on from Congregated Settings – A Strategy for Community Inclusion” was published, which identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated type settings, defined as where ten or more people reside in a single living unit or are campus based. It found that notwithstanding the commitment and initiative of dedicated staff and management, that there were a significant number of people still experiencing institutional living conditions where they lacked basic privacy and dignity, and lived their lives apart from any community and family.

The report initially recommended a seven year timeframe for the implementation of the policy and the 2016 Programme for Government identified that there should be a one- third reduction in the number of individuals residing on congregated settings by the year 2021, which reflects the continued commitment of the Government to the policy of decongregation, whilst acknowledging that the process of supporting each person to transition from a congregated setting to a community based service in a sustainable and safe way, requires planning and time.

Time to Move on from Congregated Settings is progressing and continues to demonstrate very positive results for service users who have transitioned to living in homes in community settings. Overall, the population in congregated settings is 50% lower than those identified in the original report; 16 Centres have been fully de-congregated and now there are around 1,800 people remaining in congregated settings:

- A total of 945 people had completed their transition to the community by 01/01/2020
- 6 centres have closed completely and now support residents entirely in the community
- There are 19 centres that now have less than 10 people remaining in the setting/campus.
- There are 1,494 residents (76%) now living in units with no more than nine other people and of this 343 residents (18%) are living in units with no more than three others.
- There are only 13 campus's with more than 50 residents remaining compared to 24 settings in 2012.
- In 2012 the largest campus was home to 227 residents and the largest residential building was home to 112 people. Currently, the largest campus has 145 residents and the largest residential building has 28 residents.

Further information on the *Time to Move on from Congregated Settings* can be found at the following weblink:

<https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/reports-and-publications/>

New Directions

The HSE's approach to supporting adults with disabilities who use day services in Ireland, is enshrined in the policy, *New Directions*, which proposes that 'day services' should take the form of individualised outcome-focussed supports to allow adults using those services to live a life of their choosing in accordance with their own wishes, needs and aspirations.

There is a structure set up within the nine HSE Community Healthcare Organisations (CHOs) nationally to implement *New Directions*. Each day centre provides its own programme and the type of support may differ from centre to centre. However, activities and support offered include, but are not limited to, day programmes which are essentially a support and therapeutic service designed to meet the needs of people through individual plans. The environment is designed to maximise the functional levels of service users. Day programmes provide a range of skills and activities such as independent living skills, personal development, education classes, social and recreational activities, and health-related and therapy supports.

People with disabilities, their families, carers and advocates have been actively engaged in the planning and review of the “*New Directions*” programme. They are clear that they want to do worthwhile things that fit with their interests and aspirations for their lives. Training and work are very important to them. They want to do ordinary things in ordinary places and to be part of their community. They want support to be independent and they want to be able to make choices and plans for their lives. They also want to have the support they need to do that. People want to have a say about what happens in the service they attend, to help shape policy and to influence how services are run.



Currently almost 19,000 people are in receipt of disability Day Service supports at 1,041 locations around the country. These supports are provided by approximately 95 service provider agencies.

Further information on *New Directions* and the HSE's Day Services can be found at the following weblink:

<https://www.hse.ie/eng/services/list/4/disability/newdirections/>

Progressing Disability Services for Children & Young People

The implementation of the Progressing Disability Services for Children & Young People (PDS) programme is agreed Government and HSE policy. Under the PDS programme children's disability services are changing from diagnosis based to needs based, so that all children with a disability or developmental delay have access to the right service based on their needs no matter where they live. The PDS programme will ensure that services are provided for children with complex needs regardless of where they live or where they go to school.

PDS is a significant change programme for the provision of services and supports for children from birth to 18 years of age, in line with Sláintecare and the Programme for Government, in order to:

- Provide a clear pathway and fairer access to services for all children with a disability
- Make the best use of available resources for the benefit of all children and their families
- Ensure effective teams are working in partnership with families and with education staff to support children with a disability to reach their full potential.

91 Children's Disability Network Teams (CDNTs) have been established to provide services and supports for all children with complex needs within a defined geographic area. CDNTs are teams of health and social care professionals, including nursing, occupational therapy, psychology, physiotherapy, speech and language therapy, social work and others. The teams work closely together in a family centred model, focusing on the child's and family's own priorities. Every child with complex needs now has access to a team, regardless of the nature of their disability, where they live, or the school they attend.

Since 2019, 285 development posts have been allocated to children's disability services across the country.

Further information on the Progressing Disability Services for Children and Young People Programme can be found at the following weblink:

<https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/>

UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities was adopted by the UN in 2006. Ireland signed the Convention in 2007 and ratified the Convention in 2018.

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. It applies established human rights principles from the UN Declaration on Human Rights to the situation of people with disabilities. It covers civil and political rights to equal treatment and freedom from discrimination, and social and economic rights in areas like education, health care, employment and transport. States which ratify the UN Convention commit themselves to delivering civil and political rights to people with disabilities, and to progressive realisation of social and economic rights.

The HSE is aware of an ever growing need to review the existing legislative and policy landscape to ensure same can aspire to and ultimately align with the key principles underpinning the UN Convention on the Rights of Persons with Disabilities. In this context, the HSE broadly welcomes the commitment in the Programme for Government to increase capacity across all aspects of care and to continue investment in healthcare infrastructure and equipment, together with the recommendations of the Capacity Review, in line with Project Ireland 2040.

The HSE has worked collaboratively with the Government in undertaking a Capacity Review of the Disability Sector to provide the framework within which services could develop over the coming decade. The Review accepts that significant investment across all health services over the coming 15-year period is required in tandem with a fundamental programme of reform.

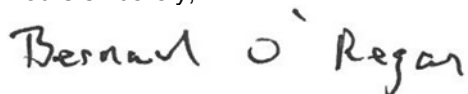


In accordance with the HSE Corporate Plan 2021-2024, the HSE will develop and implement a multi-annual funded plan for the reform of the Disability sector in line with the UN Convention, and in collaboration with government departments and agencies and disability services stakeholders.

This will mean increased services to meet demographic needs identified in the Disability Capacity Review in the context of sector reform, focusing on:

- Significant increases in Personal Assistant and Home Support hours.
- Increased and improved day services and the implementation of a refreshed and responsive New Directions policy, seeking to ensure access to appropriate and innovative developmental services and social activities.
- More appropriate residential services with a focus on community-based and supported housing options.
- Expanding centre-based and alternative respite services (e.g. home-sharing and summer camps).
- Increasing therapy services with a particular focus on multi-disciplinary needs assessment and early intervention.
- Developing the structures to enable service users to become active participants in their care and support, not only through the use of personalised budgets but also in the co-design of their services.
- Providing more people with disabilities who are currently living in congregated settings with more person-centred homes in the community.

Yours sincerely,



Bernard O'Regan
Head of Operations - Disability Services,
Community Operations